PRODUCTIVITY COMMISSION
Disability Care and Support

Thank you for the opportunity to comment on this important matter.
My understanding of the need for an improvement in the management of disability service provision in Australia comes from 21 years dealing with the system here in Victoria as a parent of a child (now a man) with autism, who still lives at home with me and my partner.

General Comments

As Charlie Rook of WA noted in his excellent and concise submission, it is very pleasing to see the scope and seriousness of this inquiry and I agree with him that that does indeed create a sense in those of us under 50 that there is cause to be hopeful yet that things may improve in Australia in the next ten years.

However as he also notes, “The range of combinations and permutations of the issues is great, and while there are many ways of achieving a suitable outcome, it should be noted that there are very many more ways of getting it wrong, than there are of getting it right.”

I certainly don’t have enough knowledge to address all those permutations, and have cherrypicked a couple of points from several sections for comment. Where I have quoted directly from the issues paper I have used bold type, and all questions in italics are from the paper.

From section 8, The Nature of Services:

‘The core formal services required for a well functioning disability care and support system are usually grouped into personal care services, respite and accommodation services, community access, community support, income support, employment, transport, aids and appliances, home modification, but also a range of intangible services, such as counselling and mentoring.’ (p. 25)

Are there any services not provided now that should be part of a national disability scheme?

There are a range of innovative programs in other countries (the TEACCH program in North Carolina in the US is a shining example) for lower functioning people with autism who are often dismissed as too difficult or disturbed and left to moulder without constructive activities in training centres in Australia.

While a lot of good work has been done in the early intervention area for people with autism in the last ten years, they have a normal life expectancy and not all of them are going to achieve a high level of functioning, but will be even harder to manage in later life if they are underoccupied.

New programs need not all be autism specific – some people benefit from the social stimulation of attending services with a range of clients, and it would be good to see a pool of flexible funding available to general service providers to assist the integration of people with autism into their programs where appropriate.

'The major Australian Government role in non-aged disability is the provision of employment services and payments of income support through programs like the Mobility Allowance, Carer Allowance and Disability Support Pension (DSP). A concern about the latter is that it is not allied with coordinated rehabilitation or other disability services, which are state responsibilities. People on the DSP rarely move to jobs or job search — and this may, in part, reflect the fact that the scheme sits in virtual isolation from the rest of the disability system.' (p.29)

What are the obstacles to a cohesive package of disability services, where do the problems most arise, and how can they be fixed? What processes might be needed to fix them?

The greatest obstacles to cohesive service provision for people with longterm disability requiring high support seem to occur at points of transition between service providers (in most states this occurs at school entry and exit age), and in the complete lack of coordination in provision of respite care, which is usually packaged by parents with minimal support from case managers.

What role would mainstream services play in any national disability scheme (such as coordination and facilitating access)?

The expertise provided by mainstream services has been achieved in a large country with a small population and less ability to amass expertise than in larger countries. Knowledge loss during transfer of services needs to be minimized as it has probably cost us a great deal more than we realise to acquire it in the first place.

I do not believe that all people with disabilities will necessarily benefit from a system where carers make all the decisions about what people need, particularly when it places service providers in a position of uncertainty about how they will be funded to maintain the service.

In the case of disabilities like autism where complex support needs place tremendous burdens on families, local centres of expertise and research, such as autism only schools where so many teachers, therapists and psychologists do placements and take their specialized experience out into general settings, are invaluable.

Larger organizations like Yooralla and Scope have developed many services that are already filling needs expertly – the new system should build on and expand these services from within by providing more funding, rather than replacing them.

Section 9. How much is needed?

Official (AIHW) estimates of unmet need shown in box 4 in this section (p. 33) are probably highly conservative since they relate only to expressed need. Moreover, they refer to the number of people, not the value of the extra services needed —I agree that this is a critical issue for determining funding.

How should unmet demand be measured and what is its size in value and person terms? Where are unmet demands greatest?

Since the AIHW estimates (of 23 600) people in 2005 were gathered with reference to respite and accommodation, the number of people failing to receive these services has undoubtedly increased dramatically as people are relinquished into the system, taking up respite and accommodation beds and fostering a culture amongst other parents of 'I'm not that badly off, I'll struggle on' - a martyr complex is easily acquired when there is little realistic hope of support and the effort required to mount a political protest is too great.

I believe unmet demand is also very pressing in aids and supports to people with physical disabilities, and I am horrified at the burdens placed on their carers when insufficient assistance is given with car and home modifications and wheelchairs. Both areas require immediate redress.

Some costs in accommodation can be addressed by increasing awareness of equity housing schemes, where they are in practice. So many young people are living at home and saving their pensions that it would not be difficult to find quite a few with at least $15,000 to assist with the funding of a supported accommodation place.

Also parents on lower incomes could be encouraged to make a greater effort to reserve some of the pension they receive in trust for their disabled family member for meeting costs in longterm care later down the track, as there is anecdotal evidence that suggests some families are already dependent on the payment they receive for their child as income.

This is really just a matter of increasing awareness of costs along a person's lifetime, instead of simply informing people of the most recent entitlement available to them in a piecemeal fashion.

Section10 Financing Options

How could a national disability scheme be used to leverage greater community contributions to the care and support of people with disabilities and their families?

It will always be important to have some kind of connection between disability services and the community, but they need not be around money.

If services are provided to a decent level, society will be rewarded by the greater integration of people with disabilities - community contributions will come in the form of greater awareness, acceptance and interest.

Section 11 Workforce issues

What type of skills and workers are required?

There is a need for an increase in the number of workers in the adult training sector with a good working understanding of functional behaviour analysis and its application in understanding clients with autism, and a better understanding of what activities can make use of the special requirements of adults with autism.

There are only a few specialist services, and spending your whole life with other clients with autism doesn't always best serve the needs of that group of autistic clients who can learn some social skills from a mixed disability group.

12. Governance and Infrastructure

How would people find out about what they were entitled to (online, one-stop shops, service providers)?

Some high-powered information brokerage would be vital. People are already confused enough! about what does and doesn’t currently exist.

What is the realistic time plan and sequence of initiatives for implementing a national disability scheme?

The initiatives of national coordination and financing should be designed fairly quickly so that money can flow into the system to service other aspects.

Are there some aspects (of an NDIS) that can be implemented early (for example, some service expansion, support to a targeted group, key infrastructure)?What are the priorities for immediate development?

While it is of fundamental importance that we design the best system we possibly can, to ensure that the failings of the present system can one day be forgotten and all Australians enjoy a first world standard disability system, longterm supported accommodation needs to be greatly expanded immediately and housing for this purpose regarded as priority infrastructure.

How much do various services cost (for example, attendant care, accommodation, day centres), and what pressures are on these costs?

I did some sums and came up with a modest figure of costs to my son of around $13,000 per year for current services accessed. I believe it is fair to add to that the loss of potential income to our family from my disappearance from the workforce due to his complex support requirements, which I estimate at around $60,000 a year including superannuation.

He has irritable bowel and does not always sleep well, and sometimes has to stay home from his service. I provide many vital connecting services as primary carer, as most of us do – we work as researchers, secretaries and copywriters for our children, communication aids creators, drivers, physical trainers, and trained observers (where behavioural supports are required.)

Adam Phillips, the psychotherapist, spoke in one of his popular books of ‘translating’ a person – I feel many of us provide this service to the community to a level that is simply not understood or appreciated at present.

While I have found it incredibly rewarding as well as challenging, it is not something you can simply dismiss as an intangible community benefit, as I am sure the Commission understands.

To this point I would argue that this kind of personalized service is probably one of the greatest costs to the system – maintaining stability and continuity of care so that intellectually disabled people can feel secure and communicate to the best of their ability is something that is usually quite expensive.

Turning the home into an institution is certainly not going to be a good longterm answer to meeting that cost, as of course you know already.

Closing comments

Thank you again for this opportunity and I hope my contribution is of some use.

I am particularly mindful of the pain and exhaustion that younger families than mine, particularly where both parents need to work, must be suffering as services continue to be restricted by the longterm accommodation crisis. Goodness knows our time during our son's adolescence was hellish enough, with regular respite. I do not know how they can be expected to bear with the current system, with its deep uncertainties and unholy and evil suppression of unmet need, for a moment longer.

Genevieve Tucker,
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